

**Title:** Bereaved donor families' experiences of organ and tissue donation, and perceived influences on their decision making

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## **Abstract**

**Purpose:** To elicit bereaved families' experiences of organ and tissue donation. A specific objective was to determine families' perceptions of how their experiences influenced donation decision-making.

**Methods:** Retrospective, qualitative interviews were undertaken with 43 participants of 31 donor families to generate rich, informative data. Participant recruitment was via 10 National Health Service Trusts, representative of five regional organ donation services in the UK. Twelve families agreed to DBD, 18 agreed to DCD, 1 unknown. Participants' responses were contextualised using a temporal framework of 'The Past', which represented families' prior knowledge, experience, attitudes, beliefs, and intentions toward organ donation; 'The Present', which incorporated the moment in time when families experienced the potential for donation; and 'The Future', which corresponded to expectations and outcomes of arising from the donation decision.

**Results:** Temporally interwoven experiences appeared to influence families' decisions to donate the organs of their deceased relative for transplantation.

**Conclusions:** The influence of temporality on donation-decision making is worthy of consideration in the planning of future education, policy, practice, and research for improved rates of family consent to donation.

## **Keywords**

deceased organ donation, family, bereavement, decision-making, consent, qualitative research

## Highlights

- A lack of donated organs means 1,000 people in the United Kingdom die each year or are too sick to receive a transplant. Others are forced to lead lives severely compromised by their organ failure and the uncertainty of organ availability.
- Improving the rate of bereaved families' consent could have a significant impact on the lives of many people.
- Research carried out in the UK elicited bereaved families' experiences of organ and tissue donation, and perceived influences on their decision making.
- Temporally interwoven experiences of Past, Present and Future appeared to influence families' decisions to donate organs of their deceased relative for transplantation.
- The influence of temporality on donation-decision making is worthy of consideration in the planning of future education, policy, practice, and research for improved rates of family consent to donation.

## 1. Introduction

Currently there are over 7,000 people in the UK on the active transplant list; however due to a lack of donated organs, 1,000 people die each year or are too sick to receive a transplant [1]. Others will be forced to lead lives severely compromised by their organ failure and the uncertainty of organ availability [2]. In 2008, the UK Government Organ Donation Taskforce [3] recommended reorganisation of donation services, targeted at increasing organ donation by 50% in five years. Despite achievement of this target, further strategic work is essential to achieving improved rates of family consent [1]. Of continuing concern is the proportion of families who refuse to allow their relative's organs to be donated or overrule their relative's expressed wish to donate [1]. Further improving the rate of family consent could have a significant impact on the lives of many people and cost savings to the National Health Service (NHS) versus alternative medical treatments. The present rate of family consent to donation in the UK suggests we are missing opportunities to support families in making a potentially life-enhancing decision.

This paper reports the findings of exploratory research carried out in the UK to elicit bereaved families' experiences of organ and tissue donation and their perceptions of how these experiences influenced donation decision-making. The study sought to build on previous evidence accrued by the research team: the influences on donation decision making [4]; the genesis of beliefs people bring to the donation discussion [5]; how people conceptualise the act of donation e.g. a 'gift of life' or a 'sacrifice' [6]; the decision-making process and bereavement issues [4] and any meaning-making of organ donation [6, 7]. To set our UK study in the prevailing Western worldview, we undertook an integrative literature review [8]. The review involved thematic network analysis [9] comprising the development of three global (core) themes of The Past, The Present and The Future [8]. These themes provided a concise temporal framework for the analysis and synthesis of new study findings.

For the duration of the study, the legislative structure for organ donation in all four countries of the UK was that of a voluntary 'opt-in' system of explicit consent to donation. Family involvement is important to the donation process, and this is practiced for moral,

ethical, legal and procedural reasons. However, the role of the family differs according to whether the donation intentions of the deceased are known [10]. Reported outcomes of the donation discussion depict a family decision to: agree or decline consent to donation in situations where there is no indication of the patient's wishes; support or overrule the expressed wishes of the deceased.

### Study design

A qualitative, exploratory design was chosen to generate rich, informative data that would lend itself to theoretical propositions as to why bereaved families agree to organ donation from a deceased relative. All permissions for this study were granted. NHS approval was given by the UK Health Department's National Research Ethics Service, West Midlands-Black Country Committee, Reference 11/WM/0313.

#### *2.1. Objectives*

In the case of bereaved families who had donation discussed with them, specific objectives were to determine:

1. Families' perceptions of how their experiences of organ and tissue donation influenced donation decision-making:
2. Whether families felt their information needs about organ donation and bereavement were met and if not, what was missing.
3. Families' views regarding any public or private recognition of donors and their families (as advocated by The Taskforce [3]).

#### *2.2. Participant identification and recruitment*

Ten NHS Trusts, representative of five regional organ donation services in the UK agreed to take part in the study. Meetings with regional and team managers of NHS Blood and Transplant (NHSBT) and Specialist Nurses-Organ Donation (SN-ODs) led to the identification of suitable study sites. Geographical spread was deemed to be important due

to potential differences in local hospital practices. SN-ODs sent a total of 99 recruitment packs to eligible participants on behalf of the research team. Recruitment was carried out in a serial manner, region by region. Purposive sampling gave preference to the most recently bereaved families. Our eligibility criteria of three to 12 months bereaved at the time of recruitment was consistent with previous work by Sque [11].

Forty-three participants from 31 families who consented to donation were retrospectively recruited during 2012-2013. Participants represented a variety of family relationships, and were bereaved a mean of seven months at the time of recruitment to the study. Twelve families agreed to DBD, 18 agreed to DCD, 1 unknown. [For further demographics of participants and their deceased relative please see Walker and Sque [12].

In accordance with NHSBT requirements and NHS Trust data protection protocols, families who declined organ donation were approached prospectively about recruitment to the study, once their visit at the hospital was complete. This procedure required the SN-OD to seek family members' agreement to be contacted about the research a minimum of three months post bereavement. Monitoring by the research team suggested a lack of compliance with the prospective recruitment strategy. Of the 108 families who declined organ donation at the 10 participating NHS Trusts, 14 (13%) were asked if they agreed to be contacted about the research, and six families agreed. One family member did not receive information due to a change of address and the remaining five family members did not respond to our invitation to join the study. Further access to family members who declined donation included ethical approval to extend the number of recruitment sites from 10 to 12. Two NHS Trusts proposed the identification of eligible participants via the SN-OD in association with the Trust bereavement service. This resulted in the implementation of a retrospective recruitment strategy involving the dissemination of 10 recruitment packs to eligible participants. However, we experienced zero family response to our invitation.

### *2.3. Data collection*

Semi-structured, audio-recorded interviews offered participants the opportunity to give an account of their experiences and to share what was important to them. Participants were offered the option of a face-to-face or telephone interview. Both methods have been successfully used with bereaved individuals [4, 6, 11]. An interview guide was developed from the literature to ensure completion of the research agenda. Questions were attentive to the objectives of the investigation and included items that illuminated: the genesis of families' beliefs about organ donation; the families' experiences of the request-approach and the discussion about donation; the course and outcome of donation decision-making, the nature of family involvement, perceptions of decision-making influences, and feelings about the donation decision; patient, and family care; sources of information and support about organ donation and bereavement. Participants were invited to provide a background to the circumstances leading to the potential for organ donation and this placed the participants' responses in context.

Once the research team received confirmation from a family member that they were willing to join the study, they were contacted by their preferred mode and a convenient date and time for the interview was arranged. Twenty-six interviews were carried out face-to-face and four by telephone. One family member provided a written response to the topics covered in the interview guide, having expressed this preference. Most interviews took place in the home environment. The interviews were mainly between one to three hours. On completion of the interview, the researcher arranged a convenient time to telephone the participant (normally in 24 to 48 hours) to check on any issues the interview may have raised and to answer any questions. Participants were offered written information of avenues for support if they thought it helpful and/or directed to appropriate professionals to discuss any issues of concern. All participants were sent a personal 'Thank You' letter and offered an executive summary of the investigation.

## *2.4. Data analysis*

Audio-recordings were transcribed verbatim and checked for accuracy while listening to the audio-recording. Listening to, and reading the transcripts facilitated recognition of important ideas and patterns, such as sequencing or repetition of experiences. Transcripts were imported into a qualitative software package (NVivo Version 8) for security and to facilitate analyses. Data collection and analysis was carried out iteratively. This entailed reflection on data already collected and the application of emergent ideas to re-focus the interview guide [13].

Qualitative content analysis, involving a directed approach to the interpretation of textual data [14] was the selected method of analysis. This involved a systematic process of applying pre-determined codes to the text and categorising the data into themes. The coding framework was based on themes developed from an integrative literature review [8] (Table 1). Cross-reference was made to the study objectives to ensure the coding framework would support the identification of relevant text. Transcripts were coded as individual units, followed by inter-case analysis. An inductive approach alongside deductive analyses facilitated new insights. Data that did not fit with an existing code were labelled separately and further analysed. This resulted in two new organising themes; Forms of recognition and Perceived outcomes.

## *2. Findings*

Global and organising themes (Table 1) provide a theoretical framework for the presentation of study findings. Exemplar quotes are presented to support our interpretations of the data, i.e. Interview [I], the study code [participant 001-031] and the death criteria [DBD or DCD]. For example, (I: 001, DCD).

### *3.1. Global theme - The Past*

#### *3.1.1. The will of the deceased person*



Most participants suggested that they were aware of their relative's wishes regarding donation. Prior knowledge of their relative's desire to donate was mostly confirmed by possession of a donor card and/or evidence of having joined the NHS Organ Donor Register. Deciding to donate when applying for a driving licence or when making a lawful will were other ways in which participants expressed understanding of their relative's wishes:

*'I actually think it was the fact that the card existed was the thing that actually clinched it, not any other persuasive arguments.'* (I: 024, DCD)

Table 1. Theoretical framework for the presentation of study findings

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**GLOBAL THEME- THE PAST**

Prior knowledge, experience, attitudes, beliefs, and intentions

<b>Organising themes</b>	<b>Basic themes</b>
The will of the deceased person	Knowledge/beliefs about the deceased person's wishes Motivation to fulfil the wishes of the deceased person Overruling the deceased person's wishes
Predispositions of family members	Prior experience of donation/transplantation Knowledge, attitudes/beliefs towards donation/ transplantation Expressed intention to be an organ donor

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**GLOBAL THEME – THE PRESENT**

The moment in time when families experienced the potential for organ donation

<b>Organising themes</b>	<b>Basic themes</b>
Intra/Interpersonal determinants	Psychological distress Protecting the deceased person's body Influences of family/friends
Comprehending the situation	Information to support decision making Knowledge, understanding and acceptance of death
The donation discussion	Timing of the approach Nature of the request-approach Characteristics of the requestor
Patient and family care	Specialist care and provision Relationships with healthcare staff Donation specific care and communication

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**GLOBAL THEME – THE FUTURE**

Perceived expectations and outcomes arising from the donation decision

<b>Organising themes</b>	<b>Basic themes</b>
Hopes and expectations	Give meaning to life/death Transcendence
Forms of recognition	Public and private tributes Personal communication
Perceived outcomes	Follow-up care and communication Bereavement issues Commitment to donation

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Decision making for family members was also supported by a belief that they were acting in accordance with their relative's personality; attributes such as helpful, kind, giving, social, compassionate, and caring. Take for example participant 018 who said her daughter; '*... cared about people. She cared about animals and different things, so why shouldn't she care about ... an opportunity to help somebody else*'; participant 003 who said her partner would have helped anyone in life so questioned; '*... why not in death?*'

Motivation to fulfil the wishes of the deceased relative was a key influence on family members' decision to donate. Many participants acknowledged their deceased relative as the decision-maker and portrayed themselves as the person responsible for fulfilling their wishes. There was also a sense of fait accompli in participant descriptions, attributed to knowing or believing that donation was their relative's choice: '*It's very straightforward. She wished it and we did it. As simple as that.*' (I: 021, DCD)

Family members also demonstrated respect for the wishes of their deceased relative when confronted with their own personal reservations about donation. A mother expressed mixed feelings when approached about donation and initially said, no; '*I was shocked when she [doctor] come in talking about it. I think that's why I said no.*' (I: 011, DBD). Motivation to fulfil the wishes of the deceased prevailed:

*'I didn't want to be wrong about saying no ... I'm going against her wishes. Because I said to [A, husband]; 'if I go against her wishes, she's not doing what she wanted and that was to help people'. And so, thinking that way ... That made me agree to it.'* (I: 011, DBD)

Determination to fulfil the wishes of the deceased was apparent when confronted with situations that threatened to overrule the prospect of donations. The parents of a teenager who died following a traumatic head injury spoke of their anguish at being told; '*there'd have to be an autopsy. So, it's that, and not donation ... to be told yes, he can [donate], then forget it, no he can't*' (I: 013, DBD). Apparently, the police conveyed this information as opposed to the healthcare staff. The parents approached their son's neurosurgeon who paved the way for donation to proceed.

### 3.1.2 Predispositions of family members

Participants disclosed a range of pre-conceived attitudes and beliefs about donation. The nature of experience ranged from immediate family situations, through to less personal circumstances of knowing a transplant recipient and through professional work. The following extract illustrates the potential for decision making to be influenced by previous experience:

*'I didn't really want the eyes to go, but being an ophthalmic nurse, I thought of all the things for me to say no to, that someone might benefit from corneal transplants.'* (I: 010, DCD)

Most participants gave indication of their own expressed intention to donate and in some cases, referred to the affirmative decision of other relatives. While some participants favoured an 'opt-out scheme' an alternative opinion was that its introduction would; *'... destroy the transplant world simply because nine out of ten will opt out immediately'* (I: 025, DBD).

## 3.2. Global Theme - The Present

### 3.2.1. Intra/Interpersonal determinants

For all participants, donation decision making took place in the context of a sudden and unexpected critical illness or event. Participants described how the initial stages of the illness or event unfolded and provided detail of the circumstances surrounding their relative's death. A key experience for many was the sudden onset and absence of any warning signs; *'I had about a minute ... where I sensed something was wrong ... But that's all. There was no warning'* (I: 025, DBD). Other participants described their relatives' sudden death as; *'like a shutter being brought down'* (I: 004, DBD) or; *'like a candle being blown out'* (I: 011, DBD).

Protecting the deceased person's body was an important issue for many participants. Perceptions of violation; *'I didn't like the idea of her being chopped up'* (I: 021, DCD); mutilation; *'You feel as though your eyes have been gouged out'* (I: 001, DCD); aesthetic destruction: *'I wanted him to look as normal as possible'* (I: 026, DCD) and prolonged

suffering; '*... he'd already been through enough*' (I: 019, DBD); '*... she should be left in peace*' (I: 020, DCD) were among participant concerns. Whilst all participants agreed to donation, personal beliefs, fears, and concerns led to the non-donation of specific organs and tissues, including the heart, the skin, bone and most often, the eyes. One participant was also protective of their relative's tissues and organs, maintaining they must be used only for transplantation:

*'I said no to ... using tissue samples and bits and bobs to use in, sort of testing anonymously... I didn't like that ... If somebody's received a kidney or heart valves from my mum, they know that someone's died and that they've got something that's helping them live, and that's quite a lovely thing for them ... But for tissue samples ... If some student doctor, whoever's going to be leaning over a microscope not caring what they're looking at ... that it won't mean anything, it'll just be a sample. And I didn't like that, not for her.'* (I: 016, DBD)

Some participants discussed how they framed the donation decision in the context of personal views about the dead body:

*'You have a spirit within you and when you die that spirit transcends to another dimension and what's left behind is just a shell. You take your personality and your character with you.'* (I: 019, DBD)

Family members and friends were identified as a major source of support for families during their experience. Decisions about donation were most often made as a family: '*I know myself, my sister and my dad were completely on board with it*' (I: 009, DCD); '*we were always a united front*' (I: 010, DCD); '*nobody was against the decision*' (I: 012, DBD).

### 3.2.2. Comprehending the situation

Most participants reported satisfaction with the information they received about their relative's condition; this being clear, direct, honest and without false hope. Participant descriptions portrayed insights into the criticality of the situation and understanding of the nature of their relative's illness/injury. Use of the terms 'brain dead' or 'brain stem dead' suggested understanding that death had occurred. A number of participants however, described their difficulty in equating death with the appearance of their relative:

*'... They told me the machine was breathing for her, but the machine was breathing for her yesterday, and she's still breathing, and that stupid bit of hope and you think someone made a mistake and she'll be okay and she'll wake up.'* (I: 016, DBD)

Families who agreed to DCD indicated understanding about the process of treatment withdrawal, and appeared satisfied with the information they received about this. Descriptive accounts suggested that treatment withdrawal took place in the environment where their relative was receiving care. An exception to this was patient and family transfer to an anaesthetic room which was remarked upon as being; *'So peaceful, so quiet'* (I: 010, DCD). It was apparent that some participants had an awareness of a time limits: (1) after treatment withdrawal and death for organ donation to proceed; *'it did depend on how long it took the heart to stop beating'* (I: 010, DCD), and (2) for saying goodbye to their relative immediately after death; *'the moment she died she would be whisked away to theatre'* (I: 001, DCD). The significance of informing families about possible timescales was highlighted by a participant who experienced non-proceeding DCD:

*'Unfortunately for us [M] didn't die; that sounds terrible again, but she didn't die within the two hours, so they couldn't go ahead with the kidney donation. But because we knew we had that timescale to work within, we knew after two hours that it wasn't going to happen. So yeah from that point of view it was good to know about the timescale.'* (I: 009, DCD)

### 3.2.3. The donation discussion

Participants' accounts revealed considerable variations in practice regarding the timing of approach about donation. A participant who was informed about a decision to withdraw life-sustaining treatment together with a request for donation said; *'I thought it was a perfectly sensible thing to do ... I saw no problem with it at all. I think the two things should be integral'*. (I: 014, DCD). Alternatively, a participant approached about DCD said:

*'I do remember thinking that this was happening all too quickly ... and I think that was part of the grieving process in that; 'wait a minute. Hang on a second. She's not dead and we're whipping bits out of her.'*" (I: 008, DCD)

Participants' descriptions indicated variable practices regarding the request-approach. A formal approach involving a meeting with the legal next-of-kin and significant family members (at the request of the decision maker) was the most common method. The professional identity and number of staff present at the time of the request suggested a collaborative approach on seven occasions, i.e. the SN-OD and medical consultant working together. The discussion usually took place in 'a room', although the setting was not always deemed fit for purpose:

*'I think we were in an office ... which was very cramped and not conducive to that kind of atmosphere.'* (I: 030, DBD)

In contrast, five family members raised the issue of donation themselves. One family suggested the doctor's response was; *'Oh I'm so glad you've brought that up ... It saves the difficult conversation'* (I: 013, DBD). Contrary to family members pre-empting the question, it was apparent that some participants were reliant on the staff to enquire, for example; *'... until they asked us, it never occurred to me'* (I: 021, DCD).

Participants described a range of emotional reactions to the approach including anticipation; *'I was waiting for this'* (I: 017, DCD); shock; *'I was totally shocked. I never expected it because I was quite convinced you see he was going to wake up'* (I: 026, DCD) and surprise; *'I just thought it was so quick. One minute she's in hospital the next thing they're asking me for organ transplant'* (I: 012, DBD). A perceived lack of prior knowledge and understanding contributed to the reactions of one family; *'If I'd known more about it [donation] then it would have been less of a shock'* (I: 018, DBD).

Participants most often recalled being approached by a member of the healthcare team caring for their relative, although participants could not always specify the role characteristics of the staff involved. Alternatively, the question was posed by a member of staff affiliated with organ donation. This latter person was rarely referred to as a SN-OD. On one occasion, the family member thought a counsellor was present, only to realise at a subsequent

meeting that this was; *'the donor nurse [SN-OD]'* (I: 002, DCD). Personal attributes of the requestor such as calm, gentle, neutral, very kind, very nice and polite were positively remarked upon, and satisfaction with the sensitivity of the approach was expressed. Some participants were sensitive to the feelings of staff involved in the approach to bereaved families about donation:

*'I think you've got to be special people to do that sort of thing ... I mean you'd have a script I suppose in your head, but still it must be ... difficult.'* (I: 012, DBD)

#### 3.2.4. Patient and family care

Most participants appeared to have a high level of confidence in medical and nursing staff expertise, and were mostly full of praise about the specialist care given to their relative and to themselves. Family satisfaction was reflected in expressions such as: I/we couldn't find fault; top class/top rate, phenomenal, brilliant, excellent, impressive, outstanding, and extremely good. The ambulance services also received praise. For example, a mother said the paramedics who treated her son were; *'like a swarm of locusts. They were just work, work, work'* (I: 013, DBD). Most participants expressed satisfaction with the way in which healthcare staff communicated with them. Interactions with SN-ODs were highly valued. There were however exceptions including counter-experiences of over sympathetic presence. Deficits in family relationships with healthcare staff predominantly related to communication issues.

Participants appeared impressed with the provision of 24-hour nursing care for their relatives, 'state of the art' technology, and the standards of personal care and communication that they observed in the specialist units. One example related to [E] who was receiving intensive care following a road traffic accident. Her mother and uncle reflected on the nature and quality of care for [E] and themselves in the context of DBD. A relationship between trust and care and the donation decision was predicted in their evaluation of the care experience:

*'But it comes down to ... The staff at the hospitals I think, how people will react to donation. It comes down to the trust that you have in those people looking after*



*your ... loved one. Because I think if it had been a different sort of care, or not quite ... I think it might have been a different decision.'* (I: 027, DBD)

Some participants raised issues about individual aspects of care such as a perceived lack of personal care, delay in getting to hospital/transfer to a specialist hospital, and differences in the standard of care delivered in specialist and generalist areas. The quality of end-of-life care was also questioned:

*'It does beg the question that if she hadn't have been a donor... how would she have been treated?'* (I: 005, DBD)

There did not appear to be any uniform standard of provision for relatives of critically ill patients, including facilities for retreat, rest, sleep, hygiene, and refreshments. Practices also varied from hospital to hospital in relation to visitation policies, restrictions on the number of people at the bedside, and car parking concessions. Accommodation for some families was limited to a waiting room that they shared with other relatives, whereas others had access to a private room during the day and/or overnight. For one participant, overnight accommodation involved payment for a room that he was required to share with a stranger. Waiting areas, seating and refreshments were identified areas for improvement. However, this did not seem to detract from participants' overall satisfaction with the care they and their relative received. Despite restricted visiting in some hospitals, participants indicated opportunity to spend time with their relative and were keen to point out how staff could be accommodating. One family suggested; *'somewhere private to reflect and grieve'* (I: 013, DBD) was most helpful during their hospital experience. In contrast, a participant described their experience in the communal waiting room as:

*'... Like going into a prison ... Quite rightly they had to secure it but there was another family there ... And just the decor ... And you were stuck ... And there was no way to communicate and you could just see people going by and you were all, you were so isolated ...'* (I: 027, DBD)

All participants suggested that they received explanation about the process of donation and that this was facilitated by one, sometimes two SN-ODs. Seven participants raised concerns about the use of a 'questionnaire' or 'checklist' [a list of questions about the lifestyle of

potential donors], which formed part of the consent process. Generally, reference was made to the length of the questionnaire, the amount of information required, a perceived lack of preparation for this part of the donation process, and surprise about what and how many organs and tissues could be donated. Expressions such as; *'intrusive'* (I: 022, DCD); *'shocking'* (I: 027, DBD); *'upsetting ... brutal'* (I: 030, DBD) and *'disturbing'* (I: 008, DCD) were representative of participant feelings. In contrast, one participant found working systematically through the form; *'quite pragmatic rather than emotional'* (I: 009, DCD) and suggested this was helpful. The following extracts illustrate participants' concerns in the context of their bereavement:

*'I totally understand why they've got to ask the questions ... I'm pretty sure the one question was 'in the last 12 months has your partner slept with another man who has slept with another man?' And I'm thinking bloody hell, you know, I've just lost the love of my life here and you're asking me if she's been cheating on me in the last, in the last 12 months.'*  
(I: 007, DBD)

*'I could feel myself shaking thinking; 'oh God I hadn't thought about it like ...' Each item was asked about ... the corneas, the heart, the lungs ... and you think; 'oh, my gosh that's really raw.' It wasn't the wrong way to do it but it was really telling.'* (I: 029, DCD)

This participant emotively described his need for information and recommended improved communication with families in the form of regular updates:

*'I could have done with some information. I was pacing. I must have done about 10 miles up and down that corridor. I must have looked at every single picture about 20 times up and down that corridor ... I would just have liked to have been told you know, this is where we are ... I think even if someone had sort of like, just turned round and sort of said; 'we think we've got one match for one of the organs or for a kidney, and you're thinking one down, three to go' or something like that ... Just giving you that ... The good news that it's going well and please stay with us.'* (I: 027, DBD)

Treating the deceased donor with respect and dignity was an important care issue for some families. Knowledge of SN-OD presence during organ retrieval appeared to provide reassurance:

*'She said I'll be with him every step of the way, when he goes down for surgery I'm there; 'I see the surgery right through to the end.' And that was a comfort to know that she was going to be there.'* (I: 019, DBD)

### 3.3. Global Theme - The Future

#### 3.3.1. Hopes and expectations

Some family members perceived consent to organ donation as giving meaning to the life and death of their relative. Through donation, participants felt that their relative's death had not been in vain and conversely, their life had not been wasted: '*... something positive was going to come out of such a tragic event.*' (I: 013, DBD). Some families pragmatically accepted the outcome of non-proceeding DCD, whereas others expressed disappointment and deflation:

*'It was sort of that feeling that you'd lost the ability to get something from ... It all just seemed completely futile ... No positivity from it at all.'* (I: 023, DCD)

#### 3.3.2. Forms of recognition

Participants disclosed a range of views when questioned about the acknowledgment of donation. Some saw public recognition as a way of promoting donation and for that reason were supportive of it. Participants who were in favour of public recognition spoke of it being a nice or lovely idea. One participant was keen to point out; '*I haven't done anything. It's not me. It's Mum that's done it, so the only personal gratification ... A nice honour in Mum's memory really, isn't it?*' (I: 002, DCD). Another participant spoke of recognition in the context of donation as a personal sacrifice:

*'They've given their life up haven't they or you feel that your loved one has given their life up? They've given something back ... They should be recognised for that.'* (I: 019, DBD)

Participants identified tributes to their deceased relative outside the context of donation, such as a personalised key ring for family and friends, a commemorative bench and the planting of trees, the development of a webpage, a book of remembrance and a memorial trophy. Aligned with the decision to donate, participants identified forms of public and private recognition, including a memorial book in the hospital that would be open to the public, and a cathedral service for donor families. Many participants discussed and/or

shared letters about the outcome of their relative's donation decision, and for some, a letter or card from recipients suggested recognition.

### 3.3.3. *Perceived outcomes*

Several families said the decision to donate had helped them in their bereavement, and gave indication of the reasons why. For example, there was evidence of personal gain through: the knowledge that donation had benefitted people; a belief that the deceased person 'lives on'; an opportunity to turn a profoundly negative situation into something positive; personal acceptance of death and bereavement, and a feeling that death was not in vain.

No participant regretted the donation decision they made at the time of their relative's death. This was affirmed in statements such as 'it was the right thing to do' or 'the right decision'. There was evidence to suggest that the donation intentions of family members' and others who were known to the deceased person had changed because of their experience. One participant explained how he went home that night and at 6am; '*... registered online, including my eyes*' (I: 024, DCD); a parent said so many of her daughter's friends had joined the organ donor register; '*oh I've been on there and I've ticked the box*' (I: 027, DBD) and a father suggested; '*it's opened everybody's eyes now to the possibility*' (I: 011, DBD).

## 4. Discussion

This study sought to elicit bereaved families' experiences of organ and tissue donation and their perceptions of how these experiences influenced their donation decision-making. We highlight important findings associated with past, present, and future dimensions of the families' temporal landscape.

### 4.1. *Global Theme - The Past*

Most families suggested that they were aware of their relative's wishes regarding donation; a known predictor for family consent [15]. Determination to fulfil the wishes of the deceased was apparent when confronted with situations that threatened to overrule the prospect of

donation such as interference by family members, the coroner, or the police. Participants disclosed a range of pre-conceived attitudes and beliefs that had the potential to negatively impact on the donation decision. It was also notable that some families disclosed a lack of knowledge about donation. The reported issues indicated a need for increased public knowledge about the donation process and campaigns to raise awareness that overcome the vagueness [16] about donation and which organs and tissues may be offered for donation, the intended outcomes of donation and the mode of death which permits this to happen.

#### *4.2. Global Theme - The Present*

In this study, the moment in time when families experienced their relative's critical illness was characterised as fluctuations of hope and despair, in which the option of organ and tissue donation appeared to assist families in their grief. Families appeared intent to turn a profoundly negative situation into something positive, and in doing so, embraced hope at the end of life [12]. Decisions about donation were most often made as a family. The receipt of clear, direct, and honest information appeared to prepare families for the catastrophic nature of the illness/injury and the reality of impending death. This was an important finding given the potential for non-donation linked to a lack of knowledge and/or understanding about the patient's illness and prognosis [17, 18] and false hopes about their recovery [18].

Most families, as also found by Morgan *et al.* [7] reported satisfaction with the quality of information they received about their relative's critical illness/injury and prognosis. This appeared to prepare families for the reality of impending death of their relative. Families' explanation and understanding of the criteria used to confirm death was variable in terms of detail and accuracy; a factor that has been linked to families who decline organ donation [19]. This was most notable in cases of DBD. Families expressed satisfaction with the sensitivity of the approach and the requestor; two important variables that are known to influence the decision to donate [6, 20, 21]. The facilities within specialist areas were not always deemed to be conducive to the sensitivity of the donation discussion, and a lack of

privacy was an issue for some grieving families. The use of a 'questionnaire' or 'checklist' which formed part of the consent process was also distressing for some families, particularly in relation to the itemisation of body parts. In one case, this resulted in the donation of fewer organs and tissues than intended at the outset. Our findings concur that the donation discussion may be enhanced by improving aspects of family care and provision [21].

Consistent with previous findings [6, 22], protecting the deceased person's body was an important issue for potential donor families, including identified perceptions of violation, mutilation, and prolonged suffering [6, 23, 24]. These concerns were seemingly dealt with by families in our study, as all agreed to donation. Rationalisation has been identified as a coping mechanism that is helpful to families in receipt of the diagnosis of brain stem death [19]. Secondary analyses of the study findings could help to develop this theory further and ascertain its relevance to circumstances of DCD. Treating the deceased donor with respect and dignity and SN-OD presence during organ retrieval were important care issues that appeared to allay families' anxieties. Personal beliefs, fears and concerns did however lead to the non-donation of specific organs and tissues, most notably the eyes, and in two cases, limited donation for transplantation only. Some families explained the non-donation of eyes for personal reasons associated with significance. There was however, an apparent lack of understanding about removal of the whole eye or the cornea for transplantation. This finding has implications for enhanced information that transmits the precise nature of the eye donation operation.

Few families who agreed to DCD gave indication of being present at the time of treatment withdrawal, but most appeared to understand what this entailed. Conversely, knowledge of possible timescales and their implications was variable. Adding to the complexity of DCD is the knowledge that unless cessation of heartbeat occurs by a pre-determined point after treatment withdrawal, donation will not be possible [25]. The study findings suggest the importance of reinforcing this information for families and assessing their need for support, especially in situations of stand-down or when death does not occur within an appropriate timescale for donation to proceed.

Families were approached about donation at varying points during their relatives' illness. Consistent with the findings of Siminoff *et al.* [26], shock or surprise was associated with increased deliberation and the potential to decline donation. Families most often recalled being approached by a member of the healthcare team caring for their relative or by a member of staff affiliated with organ donation. A collaborative request was less evident. In most cases, the approach involved a formal meeting with the legal next-of-kin. The personal distress associated with a critical, life-threatening event meant that some families overlooked the possibility of donation and were appreciative of staff that brought this to their attention. These findings support proposed action to increase consent to donation through a standard of best practice for the family approach [27] and potential strategies that could improve the deceased organ donation process for families [10]. Timely identification and referral of every potential donor to the SN-OD may also realise an increase in deceased donation through improved collaboration [28, 29].

Our findings suggested an association between positive family care experiences and consent to donation. As recommended by the National Institute for Health and Clinical Excellence [30] further research is needed to confirm this assumption. There were many examples of personalised patient and family care that contained the quality hallmarks of compassion, respect, dignity, and skilled communication. Effective communication during the donation process appeared essential to maintaining families' commitment to donation.

The concept of 'waiting' was an identified feature of families' experiences along the continuum of care; a contextual factor attributed to non-donation [31]. The length of time it took to donate was distressing for some families, and the need for regular updates from the SN-OD was an identified area for improvement. There did not appear to be any uniform standard of provision for families of critically ill patients, and families perceived a difference in the standard of care delivered in specialist and generalist areas. Visitation policies also varied from hospital to hospital. Components of care and communication in the post-donation period suggested inconsistent practice. Quality follow-up can contribute to improved understanding, recognition, and reconciliation for donor families [32].

#### *4.3. Global Theme - The Future*

Family consent to donation appeared to give meaning to the life and death of the deceased person, and for some families, was associated with a belief that their relative would 'live on' through the recipient. Generally, more participants were against any form of public recognition than in favour of it. Donation was viewed as a selfless act, for which families did not expect acknowledgement. Some families saw public recognition as a way of promoting donation or as a tribute to the deceased and for these reasons were supportive of it. The experience of donation positively influenced the donation intentions of family members and others who were known to the deceased person. Families provided evidence of personal gain through the act of donation. Consistent with previous research [33-35], this included perceptions of a positive impact on their grief and bereavement.

#### 5. Recommendations for future research

- A prospective, ethnographic, observation study to further our understanding of the minutiae of the dynamic interaction at the time of the approach and discussion about organ donation.
- Exploration of staff and family experiences of the DCD pathway to further inform potential donor and family care, and the impact of proceeding and non-proceeding DCD on family grief and bereavement.
- Causal research to test for an association between a positive family care experience and consent to donation.

#### 6. Critique of the study

We have reported the experiences and outcomes for a sample of 31 donor families who gave consent to donation. The design feature of data saturation as an indicator of sampling adequacy was not applied in this study for pragmatic reasons including pre-determined funding and timescales for completion of the work. The research should therefore be viewed



within the constraints of the purposive study sample and size. Participation was voluntary and the methodological constraints through self-selection are acknowledged. An acceptance rate of 32% is consistent with bereavement research and this type of participant [11]. Our eligibility criteria of three to 12 months bereaved at the time of recruitment resulted in a mean length of time since the donation event of 7 months. The potential for recall bias is therefore a further limitation of this retrospective study. An ethical duty of care is paramount in bereavement research, and can reconcile tensions in the study design.

Based on available data for recruitment to bereavement research, a sample of 108 families who declined donation during the study period should have supported the recruitment of 30 families, as planned. Challenges associated with the implementation of a prospective recruitment strategy were keenly observed, resulting in an inadequate study sample. We therefore acknowledge that our conclusions may have been different had the study included a comparison group of declining families. Achieving national targets for donation [1] hinge on an understanding of what is driving family refusal, as this remains a key area of organ loss. Developing an evidence-base can be strengthened through academic and clinical collaboration [36, 37]. However, for this to happen, support for SN-OD involvement in research activity needs to be balanced with service and clinical demands, together with a repertoire of research knowledge and skills to a level that promotes commitment and facilitates engagement. The safe storage of personal and case-related data of families who declined donation would enable the seemingly more favourable method of retrospective recruitment to prevail in future research. An alternative route of access to this coveted population could also be considered, for example, through the study of suddenly bereaved families' experiences of end of life care.

The Temporal Framework of Past, Present and Future, we believe, provided a unique lens to the interpretation of bereaved families' experiences of donation. The findings make an important contribution to the body of knowledge available in the UK at a time of static rates of family consent to donation [38].

## 7. Conclusion

This exploratory research has provided a state of the art temporal understanding of bereaved families' experiences of organ and tissue donation and the perceived influences on their donation decision-making. Improving family consent to donation is essential to ensure that as many people as possible receive the transplant they need. The influence of temporality on donation-decision making is worthy of consideration in the planning of future education, policy, practice, and research.

## Conflicts of interest

None.

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## **Bereaved families' experiences of organ and tissue donation**

### **Interview Guide**

#### **Background/Introductory questions**

Could you tell me a little bit about (name of person who died), the role they played in the family, and what they meant to you at the time of their death?

How did you become aware that something had happened to (name of person who died)?

Please recount the events that subsequently took place.

How would you describe the feelings you experienced at this time?

Did you have to make any special arrangements to organise family life e.g. children/work/other during this time?

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Was the topic of [as appropriate: brainstem death/cardiac death] raised with you?

How was [as appropriate: brainstem death/circulatory death], explained to you?

How was the topic of organ/tissue donation raised (when, by whom, where, who present)?

How was the discussion managed?

Is there further information you would have liked about donation at the time of the discussion?

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What were your needs (if any) at the time of making your decision? Were these needs met?

What about your needs following your decision? Were these needs met?

Were other people or relatives involved in the decision? Were children involved?

If children were involved: Tell me a little about how the children were prepared for being involved in the decision-making.

How did other relatives feel about donation?

Did their involvement influence your decision-making?

Why was it important [as appropriate: to donate/not to donate organs]?

Has this decision caused you any concern?

Did you have any concerns about organ donation?

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How do you feel about the care and treatment that (name of person who died) received?

How did you feel hospital staff treated you?

How do you feel about the facilities that were provided for you in the hospital?

How do you feel about the way in which nurses and doctors communicated with you?

What helped you the most during your hospital experience?

What caused you the most concern?

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### **Donor families only**

Were you offered any mementoes from (name of person who died) such as a lock of hair/hand print? If yes: Was this beneficial to you in any way?

Did you receive a letter from the Specialist Nurse for Organ Donation? If yes: Was this beneficial to you in any way?

Were you offered a home visit? If yes: Was this beneficial to you in any way?

Did you receive a letter from any of (name of person who died) recipients? If yes: Was this beneficial to you in any way?

Do you think there should be any public or private recognition by society of (name of person who died) contribution? If so: What would you consider a fitting recognition?

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In what ways (if any) has your life altered since this experience?

How do you feel about your donation decision?

Do you feel your views about organ donation have changed in any way since this experience? If Yes: In what way?

Has your donation decision impacted on your bereavement in any way?

What would you say have been your needs since (name of person who died) death?

Have these needs been met? If Yes: In what way? If No: What was missing in terms of care and support in your bereavement?

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### **Closing questions**

Is there anything else you would like to tell me about your experience?

How did you feel about receiving a letter inviting you to participate in this study?

Did you discuss your participation in this interview with anyone else/other family members?

What motivated you to participate in the interview?

Has participation been beneficial to you in any way?